

NIH/Carter Center Second Annual Conference on Holoprosencephaly
Family Sessions / April 9, 2002 / Session II: Research Update
Carter Center Programs and An Overview of the HPE Database
Nancy J. Clegg, R.N., C.N.S., Ph.D.
Heather N. Dountas, B.S.

The Carter Centers for Brain Research in Holoprosencephaly and Related Malformations were created to gather, store, organize, analyze and share information about HPE, but most importantly, to help families find HOPE for their children with HPE.

Why Were The Carter Centers established?

- When their son was diagnosed with HPE in 1996, Dr. Harold Urschel III, his wife, Christi Carter Urschel, and their families were overwhelmed by the misinformation about HPE, as well as the significant lack of available treatments and resources for their son. As parents, the Urschel's believed that there was hope for their son's future. In an effort to nurture this hope, their family established The Carter Centers. The Urschel's believe that if parents are given the correct information about HPE, along with available treatment options and therapy, they can more effectively coordinate the care necessary to achieve an optimal outcome for their child.

What are The Carter Centers ?

- An international, multidisciplinary treatment and research consortium, focusing on searching for new breakthrough treatments for this challenging developmental disorder.
- A worldwide network of scientists, health care professionals and patient families dedicated to accelerating progress for HPE research, treatment and education.

What are the goals of The Carter Centers ?

- Find the causes of HPE and devise prevention strategies.
- Achieve better outcomes for children with HPE through increased knowledge of the condition and by the development of more effective treatments.
- Establish an International HPE Registry and database of children diagnosed with HPE to provide a more accurate record of the number of cases currently diagnosed and the common problems affecting care.
- Focus on specific areas of study such as genetics, cognitive development, neuroimaging, motor impairments and rehabilitation therapy in order to gain a greater understanding of this disorder.
- Build a parent educational system that allows families to gain hope, guidance, support and insight.

What is the HPE Database?

- The purpose of the HPE database is to collect, analyze and share data gathered from children diagnosed with HPE in order to increase understanding of the condition and to improve treatment.
- The database contains information on demographics, family histories, exposures during pregnancy, common problems, current treatments, and results of diagnostic testing.
- The database also includes detailed images such as photographs, CT/MRI scans, and video clips.

Where are The Carter Centers located?

Clinical Centers:

- Texas Scottish Rite Hospital for Children – Dallas, TX
- Kennedy Krieger Institute affiliated with Johns Hopkins University – Baltimore, MD
- Lucile Packard Children's Hospital at Stanford – Palo Alto, CA

Research Centers:

- Harvard University – Cambridge, MA
- National Institutes of Health– Bethesda, MD
- Rutgers, The State University of New Jersey – Newark, NJ
- University of California at San Francisco – San Francisco, CA
- University of Toronto – Toronto, Canada

Where can I find more information about HPE and the Carter Centers ?

- Please visit the Carter Center webpage at <http://hpe.stanford.edu>
- Or contact Dr. Nancy Clegg at 1-800-421-1121 Ext. 8411 or Nancy.Clegg@tsrh.org